Siblings Australia Inc

NSW Education

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Siblings
australia inc

for siblings of children and adults with disability/illness

Siblings Australia welcomes the opportunity to contribute this submission to the New South Wales Parliament's Inquiry into children and young people with disability in New South Wales educational settings. Siblings Australia is the only Australian organisation to focus on the needs and contributions of siblings of people with disability over the last 25 years and has developed an international reputation for its work with families, professionals, advocacy, and contribution to research.

The terms of reference for this committee reference "the impact on children and young people with disability **and their families** associated with inadequate levels of support" and "the benefits for all children and young people if students with disability are provided with adequate levels of support."

Often, at a policy level, the discussion about "family supports" with regards to people with disability is shorthand for "parental supports." The needs of siblings are overlooked. This should not be the case.

In all situations where there is any kind of disability or illness, the whole family is impacted. Importantly, young people who are siblings do not often have the emotional and cognitive maturity to cope with what is happening around them. Siblings Australia would argue that there needs to be more consideration given to the mental health and well-being of both the person with disability and their sibling(s) and also the strength of the relationship between siblings. Not only will this benefit the sibling but a stronger relationship (given the sibling relationship will likely be the longest of any) will have huge impacts on the well-being, social inclusion and safeguarding of the person with disability over their lifetime.

As diagnosis of a disability often occurs in childhood, siblings can be overlooked as family attention focuses on the needs of the person with the disability and their immediate requirements. While understandable, the needs of siblings cannot be overlooked.

Siblings of people with disability are vulnerable too.[1]The issues for siblings of people with disability can be complex. Each person has a unique set of internal characteristics and external challenges and there are several factors that affect their adjustment to these. Even within one family, siblings may respond very differently to what is happening around them. And their experiences and reactions will change over their lifetime.

It is well-accepted that disability impacts the whole family. A 2008 Australian Institute of Family Studies report[2] found that parents of children with disability have higher rates of depression than the general population and siblings also had a significantly increased risk of depression, regardless of any caring role. Often these parents do not access services for themselves or their other children as the focus is on the child with disability. If they do recognize the challenges for siblings, support options are limited.

Siblings can experience significant stress, confusion, and difficult feelings like grief, guilt, anger, fear and embarrassment. There is also a lot of pressure on them to not 'make waves', to be perfect and not add to any stress for parents. They might try to squash any of the difficulties they face and rarely ask for help themselves, which then increases the risk of mental and physical health problems[3].

[1] Lamorey, Suzanne. (1999). Parentification of Siblings of Children with Disability or Chronic Disease. In Nancy D. Chase (Ed.), Burdened Children: Theory, Research and Treatment of Parentification. Thousand Oaks, California: Sage Publications

[2] Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N., Kingston, M. (2008). The nature and impact of caring for family members with a disability in Australia. Australian Institute of Family Studies, 2008.Research Report, no. 16

[3] Hogan, D., Park, J., & Goldscheider, F. (2003). Using Survey Data to Study Disability: Results From the National Health Interview Survey on Disability. Research in Social Science and Disability, 3, 185-205.

As the RANZCP stated in an issues paper regarding siblings, *'There is reasonable consensus that siblings of children with chronic conditions are at risk for behavioural, mental and physical health problems. If left unaddressed, the challenges which siblings face can increase their risk of developing longer term mental health problems, at considerable cost to them, governments, and the community.*' (see this and other related documents here).

Siblings have been highlighted as being at risk in other publications from various sectors (these publications are available upon request).

Siblings Australia's own Mapping Project from 2018 highlighted the contribution and needs of siblings, the gaps in services, and offered recommendations for the future.

Siblings can also play an important role in the development of young people with disability. The relationship between siblings is often the longest of a lifetime. If this relationship is strengthened and nurtured from a young age it can set up better outcomes for both children going forward. A strong relationship between siblings can enhance the well-being, social inclusion, and safety of a young person with disability.

The Autism CRC highlighted that siblings were significant 'agents' in the development of young people with autism in their report Interventions for children on the autism spectrum: A synthesis of research evidence.

Siblings Australia's white paper, 'Why are siblings important to achieving disability policy goals in Australia?' considered the many ways in which siblings do, or could (if better supported and acknowledged) help with achieving the goals of the Australian Disability Strategy. As highlighted in that paper, by virtue of being in a relatively peer-like sibling relationship, often with a more egalitarian or 'horizontal' power dynamic than people with disability commonly have with a range of others in their lives, siblings *want* their brother or sister to have as many of the same opportunities in life as themselves as possible and do not want to have undue responsibility for their brother or sister with disability. Better supported siblings can, in turn, support people with disability to live the good life.

Government understanding of and approach to siblings is not nuanced enough at present to comprehend the gamut of experiences lived by siblings. The term "glass children" or "well child syndrome" is one that has been gaining traction for siblings through social media to help them understand their own experiences. This phenomenon is used to describe siblings who feel as though they have been "looked through" because the needs of their brother or sister with a disability or chronic illness were given priority.

These young people can feel an overwhelming pressure to be problem-free; they may have a hard time expressing their emotions because they do not feel they are given space to do so; they can be people-pleasing to their own detriment. They can feel like they are inconveniencing people when they have their own problems and can go on to neglect their own needs in relationships.

Long-term, this "invisibility" can impact on their sense of self and their relationships with others.

There has been some attempt to include siblings under the 'young carer' policy, but this is not necessarily in the best interests of siblings nor the young person with disability.

Not only does the focus on the young carer model only further thrust expectations on young people that they may not wish to take; but it can also interfere with the natural relationship between brothers and sisters. For a truly inclusive approach, the "ordinary" needs to be celebrated and supported. That means supporting siblings in their role and

not as young carers. While siblings may provide some level of caregiving, assuming a carer relationship suggests a hierarchical structure between siblings that is not inclusive and does not support the natural relationship between brothers and sisters. It does not necessarily afford the child with disability the dignity to which they should be afforded.

Siblings Australia is currently undertaking a survey of families that engage with our services. When asked what they wish people at school knew about being a sibling, responses have included:

- "Please treat me as an individual. I don't want to look after my brothers in the playground and at OSHC. I feel overwhelmed."
- "Know I may be processing difficult experiences I have at home when I'm not concentrating, so offer me compassion. Help me with healthy social interactions as I'm used to having my life controlled by my brother."
- "To not ask me for help with my sibling and interrupt my learning."
- "Understand that half my time is spend [*sic*] helping my sibling, and I don't have a lot of time for other things."

While only a small selection, these comments reflect what siblings have been telling Siblings Australia for years. Too often, teachers do not understand the sibling experience; and too often, teachers and educators seek support from siblings to help with the behaviours and actions of their brother or sister with a disability. This is not fair to the siblings to expect them to manage situations trained adults are not able to. Additionally, it can impact significantly their education to have their learning interrupted.

Research demonstrates the impact of being sibling of a person with disability can lead to complex mental health considerations. As a cohort, siblings are significantly more likely than the general population to suffer depression, anxiety, and stress.

This should be given due consideration in this review. Not only do well-supported siblings have less of their own issues; they are better able to support their brother or sister.

There needs to be better identification, through systematic and organised outreach, of children at risk, including those that are not obvious or who do not speak up about their struggles. This needs to be through all the settings in which a sibling operates – including schools – and not left to parents to manage.

Peer-to-peer supports and resources, co-designed with young people and those who work in this space, could help improve their social and emotional well-being. Recognition of the impacts of being a sibling should also be prioritized.

True inclusion is achieved when people can experience the magic of the ordinary. Supporting young people with disability to engage with their siblings as a brother or sister, without the assumption of a caring role, helps those with disability achieve greater inclusion.

Siblings Australia urges the committee to consider the needs of all family members when making recommendations about how inclusive education could best operate in New South Wales.